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ABSTRACT

This final report describes activities and accomplishments of the Illinois state project on services for children with deaf-blindness, a 3-year federally supported project to address the needs of children (ages birth to 21) who are deaf-blind. Project activities included inservice training and technical assistance, development of a comprehensive resource library, the maintenance of a statewide census of students with deaf-blindness, and assistance in assuring appropriate educational services to these children. Project staff were involved in Child Find activities, individual program development, family consultation, program consultation, and inservice trainings. An overall intent of the project was to integrate infants and toddlers with deaf-blindness into the existing early intervention service delivery system. Approximately 340 diagnostic assessments for children with dual sensory impairments were conducted. Other accomplishments included the expansion of a Toy Lending Library for families and sponsoring of an annual Family Training Weekend. An Interagency Agreement Committee met regularly to assist school graduates in the transition to adult service programs. Annual needs assessments were also conducted. Individual sections of the report describe the project's goals and objectives, conceptual framework, activities and accomplishments, project changes, evaluation findings, and impact. (DB)

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SERVICES FOR CHILDREN WITH DEAF-BLINDNESS
CFDA-84.025A - STATE PROJECT

FINAL PERFORMANCE REPORT

PROJECT NUMBER: H025A2005

PROJECT START DATE: October 1, 1992
PROJECT END DATE: September 30, 1995

PROJECT TITLE: Illinois State Project:
Services for Children with
Deaf-Blindness Program

GEOGRAPHIC AREA SERVED: Illinois

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EXECUTIVE SUMMARY

Illinois State Project: Services for Children with Deaf-Blindness Program

The Illinois State Project: Services for Children with Deaf-Blindness Program was designed to address needs of children between the ages of birth-to-twenty-one who are deaf-blind. These services were provided through a contract between the Illinois State Board of Education and the Philip J. Rock Center. The Center provides a variety of resources to all Illinois residents who are deaf-blind. Specific activities of the Center that complement the goals of the grant project include inservice training and technical assistance, a comprehensive resource library, the maintenance of a state-wide census of students who are deaf-blind, and assistance in assuring appropriate educational services to children who are deaf-blind.

Goals for the project were:

I. To assist current service providers in identifying children with deaf-blindness.

II. To assure that all infants and toddlers suspected of being deaf-blind are seen for necessary assessments.

III. To assure that all infants and toddlers identified with deaf-blindness are receiving educational and support services.

IV. To provide technical assistance to service providers and parents of children with deaf-blindness.

The Philip J. Rock Center employed seven specialists through the 307.11 federal grant project. During these past three years, the Specialists engaged in activities of Child Find, individual program development, family consultation and program consultation. They presented at in-service trainings and were available to share resources and information.

It was a primary responsibility of the project specialists to establish a working relationship with the early intervention service providers in their respective geographic areas. The overall intent of the project was not to create a separate service system for the population; but rather to integrate infants and toddlers who are deaf-blind into the existing early intervention service delivery system and utilize a collaborative approach. Cnly when local services were not available due to a total lack of availability or a waiting list was direct services offered with 307.11 money. In the instance of serving infants and toddlers where there were waiting lists, the local early intervention service provider was kept informed and supportive services accessed where possible.

The project supported attendance of 1260 people to inservices, conferences, and training workshops.

Three hundred forty-four diagnostics for children with dual sensory impairments were scheduled and paid for by the project. They included: occupational therapy evaluations, physical therapy evaluations, ophthalmological evaluations, audiological evaluations, low vision evaluations, oral motor evaluations, visual evoked response evaluations, speech & language evaluations, auditory brainstem response evaluations and neurological consultations.

Other accomplishments include the expansion of a Toy Lending Library for families, and the sponsoring of an annual Family Training Weekend for 20-40 families.

The Philip J. Rock Center hosted bimonthly meetings in central Illinois for an Interagency Agreement Committee (IAC). Representatives from the state agencies met to share information and discuss strategies to address servi e delivery "gaps". The Interagency Agreement Committee hosted an annual conference to increase awareness and provide pertinent programming information on deaf-blindness. IAC was established to assist transitional school graduates in the transition to adult service programs. The project provided technical assistance to 15 adult service sites. All professionals working with individuals who are deaf-blind, their families and consumers had access to all services provided by the Center and project.

An annual needs assessment and the lack of mandated services for the infant and toddler age group have resulted in the State of Illinois concentrating its efforts on meeting the needs of this population with the 307.11 project. The results of the annual needs assessment showed a lack of expertise by service providers in the identification of infants and toddlers who are deaf-blind as well as in meeting the needs of these children. In many instances, this was due to the low incidence of the handicapping condition. In 1989, of the approximately 294 children who were deaf-blind in Illinois, only 35 were between the ages of birth-to-three. As a result of the diagnostic identification activities initiated under this grant, infants and toddlers with dual auditory-visual deficits have been identified and are receiving services.

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GOALS AND OBJECTIVES

I. **To assist current service providers in identifying children with deaf-blindness.**

A. Modify the inservice training module that is presented to service providers in Illinois.

1. Based on the evaluation of inservices given during the prior year; the Center will make modifications in the training module used for presentations to Early Intervention Centers.

2. Specialists will have the opportunity to review revisions and give feedback.

3. Revised module will be available for presentations. Information packets will be developed from the training module materials to be distributed to medical centers and doctors' offices.

4. An inservice training module will be developed that is specifically targeted for presentation to school personnel.

B. Hire Deaf-Blind Specialists to implement grant activities.

1. The Center's Chief Administrator will assure that positions remain filled with qualified staff.

C. Offer consultation services, following presentations of the inservice training module.

1. Upon request from a service provider, the Specialist will observe the child suspected of being deaf-blind and consults with parents and service providers.

2. Informal functional vision and auditory checklists will be completed.

3. Current records will be reviewed to determine status of vision and hearing, as well as other disabilities.

4. Determination will be made regarding a need to refer for medical and educational evaluations.

D. Maintain contact with service providers and parents.

1. Regardless of the presence of a child with deaf-blindness within a given program, the Specialists will make contact on a quarterly basis.

2. Parents will be contacted on a quarterly basis.

3. Written summaries of all contacts will be prepared by the Specialists and sent to the Center.

4. All information required for the Deaf-Blind Registry will be maintained and updated on as semi-annual basis.

II. To assure that infants and toddlers suspected of being deaf-blind are seen for necessary assessments.

A. Contract for the provision of diagnostics.

1. Infants and toddlers maybe referred by parents or service providers for diagnostics to the Center.

2. The Chief Administrator will review requests and determines appropriateness and eligibility for services.

3. If eligible, referral will be made to the appropriate diagnostic center.

4. All findings will be returned in written form to the Center.

B. Share results of diagnostics with parents and service providers.

1. Upon receipt, copies of written diagnostic reports will be mailed to service providers and parents.

2. When indicated, a meeting will be scheduled to discuss the results of the evaluations.

C. Facilitate the implementation of all diagnostic recommendations.

1. Implementation strategies of recommendations will be discussed with parents and service providers.

2. If further assessments are necessary, the Center will make arrangements for appointments.

3. If programmatic modifications are necessary, the Specialist will work with the program staff to implement change.

4. If necessary, outside consultants may be contracted with to provide services.

D. Facilitate the development of service delivery plans.

1. Using the Individualized Family Service Plan (IFSP), goals and objectives will be written for the infant or toddler and his/her family.

2. The Specialist will assist the service provider and family as needed in the implementation of the IFSP.

3. As needed, the Specialist will facilitate the procurement of additional support services for the infant or toddler, service provider, and parents (e.g. public assistance, respite services, counseling, etc.).

III. To assure that all infants and toddlers identified with deaf-blindness are receiving educational and support services.

A. Make contacts with local service providers to provide services.

1. If an infant or toddler is already known to a local agency, the Specialist will work with this agency to provide direct service.

2. If an infant of toddler is not known to a local agency, the Specialist will identify

and make contact with the appropriate agency.

3. Using the Center's Contact Summary Form, copies of all activities on behalf of an infant or toddler will be written up and shared with parents, service providers and the Center's Chief Administrator.

B. Provide direct services on a weekly basis, when adequate services are not available through existing service providers.

1. Services will be provided on a homebound basis when possible.

2. Center-based services will be provided when homebound services are not feasible.

3. Weekly written summaries of activities will be written on the Contact Summary Form and prepared with one copy remaining with the parent, one copy with the service provider and one copy maintained in the files at the Philip Rock Center.

C. Provide support services.

1. The Specialist will assist the family in securing necessary support services (e.g. occupational therapy, physical therapy, speech and language therapy etc.).

2. The Specialist will be responsible for processing referral requests for additional diagnostics when updated evaluation information is needed.

IV. To provide technical assistance to service providers and parents of children with deaf-blindness.

A. Provide consultation services to programs as needed.

1. Consultation services may be requested by parents or service providers by submitting a referral form to the Center.

2. Update the Center's Technical Assistance manual on deaf-blindness.

3. Lend periodicals, videos and toys from the Center's library to parents and service providers.

4. Plan a Parent Family Training Weekend to provide parents with speakers on topics of interest to them and provide their children with childcare activities.

B. Work with IAC to oversee the delivery of transition services.

1. IAC will review cases to assist in the coordination of services for individuals as they change placements or services.

2. Representatives from the various state agencies will share information and resources .

C. Plan the annual IAC conference for parents, teachers and service providers.

1. A statewide conference will be organized for the winter season.

2. Presentations will be scheduled on the topics of early intervention, education, transition, vocational, and related services to children with deaf-blindness.

3. Evaluate the conference's effectiveness with written evaluation.

CONCEPTUAL FRAMEWORK

Due to the low incidence and multiple nature of their disabilities, students with dual sensory impairments pose unique challenges to the educational system in terms of (a) curriculum, (b) instruction, (c) receiving education within general education schools/classrooms, (d) planning for meaningful transitions, and (e) post-school opportunities (Covert & Carr, 1988; Ellis, 1986; Goetz, Guess, & Stremel-Campbell, 1987; Helmstetter, Murphy-Herd, Roberts, & Guess, 1987).

Integration into community services and opportunities for social interactions are crucial components of appropriate intervention programs for young children with multiple disabilities. However, because the developmental, health, and family-related needs of young children differ from those of older children, the successful integration of infants and toddlers requires careful consideration of the unique issues facing children of this age range and their families (Hanson & Hanline, 1989).

According to Hanline and Hanson (1989), interventions in the early years must be family focused and utilize community-based programs whenever possible. When parents and professionals work together to integrate children with disabilities into community child care and educational activities, the needs of the family and the child are more likely to be met. Through such preparation, support, and advocacy, families of children with disabilities are given the same opportunities as other families to fully take advantage of child-related community resources.

Downing and Eichinger (1990) found that, classroom teachers of students without sensory impairments usually are not experienced with learners having dual deficits and may be unfamiliar with strategies that compensate for sensory losses. However, if these teachers can be encouraged to seek assistance from specialists as needed, and to recognize the importance of adapting to the sensory loss, meeting the needs of students with dual sensory impairments can be achieved without jeopardizing the instruction of other students.

Learners with dual sensory impairments (deaf-blindness) traditionally have been educated in segregated and specialized environments. These learners, however, possess many of the same characteristics as other learners with severe disabilities who have been successfully integrated into regular schools and classes (Ford & Davern, 1989).

As Durand and Kishi (1987) found, in some instances staff lacked knowledge of current best practices and may have

needed additional supports and supervision to ensure continued utilization of new skills rather than reversion to past, ineffective reaction patterns whenever old patterns resurfaced.

According to Janney and Meyer (1990), consultants and inservice trainers may need to work more closely with school and district administrators to ensure that organizational mechanisms to support implementation and maintenance of effective practices are in place.

PROJECT ACTIVITIES/ACCOMPLISHMENTS

I. **To assist current service providers in identifying children with deaf-blindness.**

Based on the evaluation of inservices given during the prior year, the Center made modifications in the training module each Fall. Presentations were given to early intervention centers and community service providers. Deaf-blind Specialists had the opportunity to review and participate in the revisions for the final draft of the training module. The revised training module is available for presentations. Information packets have been updated from the training module materials to be distributed to medical centers and doctors' offices. One inservice training module has been designed specifically for presentations to school personnel.

The Center's Chief Administrator has hired qualified and competent staff for all Specialists' positions. Upon request from community service providers, the Specialists observed children suspected of being deaf-blind and provided technical assistance to parents and service providers. Informal functional vision and auditory checklists were completed for each new referral to the center. Current records were reviewed to determine the child's status of vision and hearing, as well as other disabilities. Determination was made regarding a need to refer for medical and educational evaluations.

Quarterly contacts were made by the specialists to programs currently serving children with deaf-blindness and to programs that are likely to serve children with dual sensory impairments. Parents of children with deaf-blindness received quarterly newsletters and written reports following each contact. Written summaries of all contacts were prepared by the Specialists and reviewed by the Chief Administrator and maintained on file at the Center. All information required for the Deaf-Blind Census was maintained and updated on a semi-annual basis. There are currently 384 children on the Illinois Census.

II. **To assure that infants and toddlers suspected of being deaf-blind are seen for necessary assessments.**

Infants and toddlers were referred by parents or service providers for diagnostics to the Center. The Chief Administrator reviewed diagnostic requests and determined appropriateness and eligibility for services. When eligible, referrals were made to the appropriate diagnostic center. All diagnostic

findings were submitted in written form to the Center. Upon receipt, copies of written diagnostic reports were mailed to service providers and parents. When indicated, a meeting was scheduled to discuss the results of the evaluations with team members. Implementation strategies of recommendations were discussed with parents and service providers. When further assessments were necessary, the Center made arrangements for appointments.

When programmatic modifications were necessary, the Specialist worked with the program staff to implement change. When necessary, outside consultants were contracted with to provide services. Using the Individualized Family Service Plan (IFSP), goals and objectives were written for the infant or toddler and his/her family. The Specialist assisted the service provider and family as needed in the implementation of the IFSP. As needed, the Specialist facilitated the procurement of additional support services for the infant or toddler, service provider, and parents (e.g. public assistance, respite services, counseling, etc.).

III. **To assure that all infants and toddlers identified with deaf-blindness are receiving educational and support services.**

If an infant or toddler was already known to a local agency, the Specialist works with this agency to provide direct service. If an infant or toddler was not known to a local agency, the Specialist identified and made contact with the appropriate agency. Using the Center's Contact Summary Form, copies of all activities on behalf of an infant or toddler were written and shared with parents, service providers and the Center's Chief Administrator. Services were provided on a homebound basis when possible. Center-based services were provided when homebound services were not feasible.

Weekly written summaries of activities were written on the Contact Summary Form and prepared with one copy remaining with the parent, one copy with the service provider and one copy maintained in the files at the Philip Rock Center. The Specialists assisted family members in securing necessary support services (e.g. occupational therapy, physical therapy, speech and language therapy etc.). The Specialists were responsible for processing referral requests for additional diagnostics when updated evaluation information was needed.

IV. **To provide technical assistance to service providers and parents of children with deaf-blindness.**

Consultation services were requested by parents or service providers by submitting a referral form to the Center. Periodicals, videos and toys from the Center's library were loaned to parents and service providers.

A Parent Family Training Weekend to provide parents with speakers on topics of interest to them and provide their children with childcare activities was scheduled all three summers.

Interagency Agreement Committee reviewed cases to assist in the coordination of services for individuals as they change placements or services. Representatives from the various state agencies shared information and resources at bimonthly meetings. A statewide conference was planned all three years. Presentations were scheduled on the topics of communication and orientation/mobility curriculum. Sessions will be offered to parents on the topic of Empowerment and for consumers who are deaf-blind on accessing community services. The conference's effectiveness was evaluated with written evaluation.

PROJECT CHANGES

In the third year of the Illinois 307.11 project, the OSEP grant officer requested the project activities relating to "early intervention direct services" be changed to "early intervention technical assistance". The rationale behind this request stemmed from the Illinois State Board of Education receiving federal Part H dollars for all infants and toddlers. The Philip Rock Center was successful in receiving a state grant for Part H monies targeted for children with deaf-blindness. The activities of the 307.11 project and the Part H grant for children with deaf-blindness are both coordinated by the Philip Rock Center Chief Administrator.

EVALUATION FINDINGS

Evaluation of the project activities consisted of the following components. The Philip J. Rock Center Chief Administrator met with the seven specialists on a bimonthly basis to monitor grant activities. Copies of all activity summary sheets and calendars were mailed to the Center monthly. All staff were evaluated annually. Programs receiving technical assistance were asked to evaluate the quality and effectiveness of the assistance provided. Parents who were the recipients of direct service, consultation and/or diagnostic services were asked to complete a satisfaction survey.

The families and service providers that received services from this project indicated the following:

1. There are still children with dual sensory impairments that are not being identified and consequently not receiving appropriate services.

2. All of the families that participated in the Family Training Weekend felt that the times was well spent. The received information related to the field of deaf-blindness and were able to network with other parents.

3. Parents turned to the Center to fund diagnostics when all other funding sources had been exhausted. These diagnostics provided valuable information for programming decisions.

4. Parents and service providers appreciated being able to call the Philip Rock Center to have questions answered or referrals made on their behalf.

5. The Interagency Agreement Committee provided an important resource for educators, adult service providers and parents, especially in the area of transition from school.

6. Parents requested help establishing a statewide parents organization.

PROJECT IMPACT

The following chart is a count (per person) of all contacts made by the Illinois Deaf-Blind Specialists during the course of their work on the 307.11 project for the 3 year grant period.

	PROFESSIONAL	PARAPROFESSIONAL	FAMILY MEMBER
I. CONSULTATIVE SERVICES			
A. Direct service ages 0-2 (FY93/FY94 only)	883	185	2567
B. # of technical assistance visits, ages 0-2	622	83	906
C. # of technical assistance visit. ages 3-21	988	225	532
TOTAL CONSULTATIVE SERVICES	2493	493	4005
II. TRAINING			
A. Inservices given	984	242	34
III. INFORMATION/ REFERRAL SERVICES			
A. Phone consultations	2269	73	1400
B. Materials Requests (photocopies or loans)	625	64	403
TOTAL INFORMATION REFERRAL	2894	147	1803

State Geographic Assignments for Specialists

Area I
Northeast

Area II
Northwest

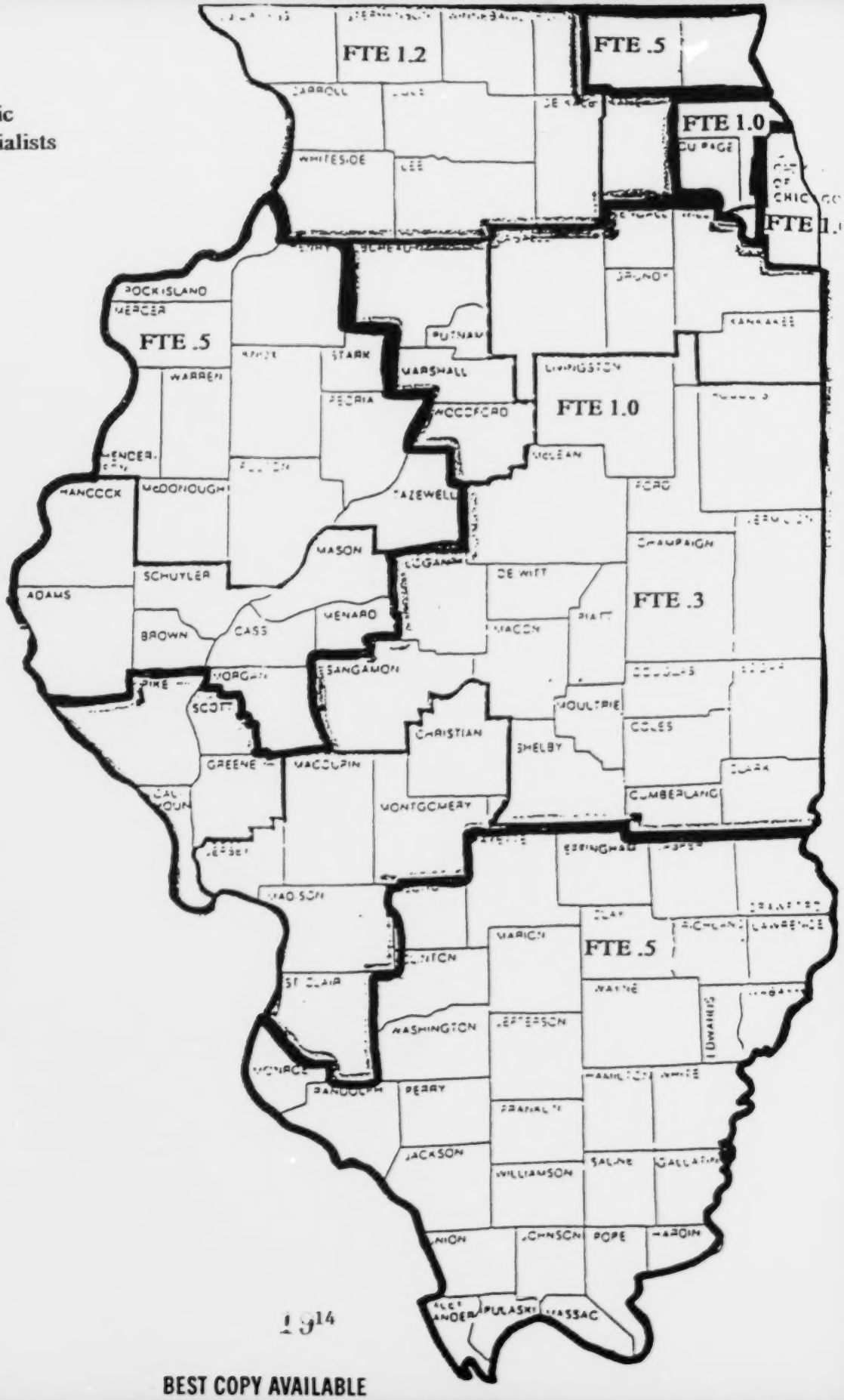
Area III
Chicago

Area IV
Chicago Suburbs

Area V
East Central

Area VI
West Central

Area VII
South



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INFORMATION

Further information can be found by contacting the Philip J. Rock Center, ERIC or DB-LINK.

The Philip Rock Center maintains records on all technical assistance visits and inservice trainings. Copies of agenda, handouts and evaluation forms are available on request.

ASSURANCE STATEMENT

The Illinois State Project Services for Children with Deaf-Blindness Program Final Report has been sent to the ERIC Clearinghouse, Reston, Virginia.